

## II. Early Intervention

### A. What Are Early Intervention Services?

Early Intervention services are designed for infants and toddlers (from birth through age three) who are not developing as expected or who have a condition that can delay normal development. When appropriate services and supports are made available as soon as possible to these infants and toddlers, significant long-term benefits for those children and their families result. In some cases, the need for special services later in life may be decreased or eliminated; and even if continued supports are needed, the opportunity for the child to grow and develop to his or her full potential is enhanced.

Early Intervention services focus on increasing a child's ability to participate in family and community life. Typically, an "Early Intervention specialist" works with the child and family to identify treatment needs, gather resources and information, and coordinate therapy and other intervention services. Further support for the child and family is provided by a multidisciplinary team that may include occupational, physical, and speech/language therapists as well as other appropriate service providers. Parents and other caregivers are taught to use everyday "learning" activities to help the child progress in his or her physical and cognitive development. In Virginia, Early Intervention services are provided through the **Infant and Toddler Connection**.

Part C of the federal Individuals with Disabilities Education Improvement Act, P.L. 108-446 (IDEA) provides authorization for Early Intervention services; and these services are typically referred to simply as **Part C**. Virginia has participated in the Part C program since its inception in 1974. Part C services are guided by state statute through the *Code of Virginia*, §§ 2.2-5300–5308. Eight state agencies share responsibility for providing Part C services through the Virginia Interagency Coordinating Council: the Departments for the Blind and Vision Impaired, Deaf and Hard of Hearing, Education, Health, Social Services, Medical Assistance Services, and Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) as well as the Virginia Office for Protection and Advocacy. Of these, DMHMRSAS is designated as the lead state agency accountable to the federal Office of Special Education Programs of the U.S. Department of Education for ensuring that Virginia's Part C services meet all applicable federal regulations and guidelines; and ensuring the quality of service delivery.

In its role as lead agency **DMHMRSAS** has worked closely with its state agency and local partners to improve services to infants and toddlers throughout the state as well as to enhance the operations of the Part C program as a whole. This work has included significant improvements to its data and reporting systems. Training and technical assistance have been provided throughout the state, and compliance on several key indicators of services to children has improved dramatically. Over the course of the last two years, DMHMRSAS has worked with an outside consultant, Solutions Consulting Group, LLC. The consultants evaluated various components of the Part C system and key results of their most recent report, *System of Payments Summary Report*, will be referenced throughout the chapter.

## B. Who Is Eligible for Early Intervention Services?

Every state develops its own definition of eligibility for Part C Early Intervention services. In Virginia, as required in the *Code of Virginia*, § 2.2-5300, children from birth to age three and their families are eligible for Part C services when a determination has been made that the child has:

- ✓ a developmental delay of at least 25 percent in one of the developmental domains of cognition, communication, motor, adaptive, or social/emotional; and
- ✓ atypical development; and/or
- ✓ a diagnosed physical or mental disability that has a high probability of resulting in developmental delay (e.g., significant central nervous system anomaly, congenital or acquired hearing loss, chromosomal abnormalities, and inborn errors of the metabolism).

To be eligible for Part C services, an infant or toddler must meet the criteria above after having been evaluated by at least two professionals whose backgrounds are in different areas of child development. Eligibility is determined by the local **Infant and Toddler Connection** lead agency. Part C services are available to all eligible children regardless of their families' ability to pay.

## C. How Are Early Intervention Services Accessed and Delivered?

As the state lead agency for Part C services (*Code of Virginia*, § 2.2-5304), the **Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)** is responsible for supervising and monitoring Virginia's Early Intervention system and for ensuring both the quality of service delivery and compliance with federal regulations. Through its **Office of Child and Family Services**, DMHMRSAS establishes regulations and adopts statewide policies and procedures to ensure consistent and equitable access to Part C services. It also manages the statewide interagency system that coordinates Early Intervention services.

The Part C system emphasizes local decision-making and autonomy in service implementation with state-level accountability for consistency in quality and availability of services. The *Code of Virginia* specifically does not mandate that localities provide funding for any costs under the Part C Early Intervention system, either directly or indirectly through their participating local public agencies. Localities, nevertheless, are involved in identifying alternative funding sources where available, and many contribute funds to Part C.

The Part C system accentuates understanding by the professional and lay communities of the wide range of developmental delays and disabilities encountered in early childhood, the recognition of the benefits of early identification and response, and the importance of a team approach focusing on the individual needs of each child and family. As with other disability-related services, local geography, service availability, populations served, political jurisdictions

served, and organizational structure are among the variables of local systems. In some areas, personnel shortages contribute to a wide variability in services between localities.

In its administration of the system, DMHMRSAS contracts with 40 **local lead agencies** (local **Infant and Toddler Connection** entities), which are designated by the local city or county government. Currently 33 Community Services Boards (CSBs) serve as local lead agencies for Part C services. Lead agencies for the remaining localities include 2 public schools, 2 universities, 2 local social services departments, and 1 local health department. The local lead agency is required to designate a single point of entry for the local system, which is usually, but not always, itself.

The local lead agencies are responsible for budget management, allocation of federal and state Part C funds, collection and reporting of information on local service providers and levels of participation, and conducting Child Find activities. **Child Find**, a federal mandate under the Individuals with Disabilities Education Improvement Act (IDEA), requires that the local lead agencies identify infants and toddlers who may be eligible for Part C services and conduct public awareness campaigns designed to encourage referrals to and use of the Early Intervention system.

The local lead agencies are also responsible for **local service delivery**. They determine eligibility and provide service coordinators (case managers) who guide families through the Early Intervention process and who facilitate the development and implementation of required **Individualized Family Services Plans (IFSP)**. Each IFSP is the result of collaboration between direct service providers, who include representatives from the Departments of Health, of Social Services, and of Education; Community Services Boards; and networks of private providers. The IFSP lists the outcomes that the family and Part C team would like to see for the child and identifies the services and supports needed to meet those outcomes. Family participation is a fundamental part of the IFSP process, ensuring that it corresponds to their resources, concerns, and priorities.

Forty **Local Interagency Coordinating Councils (LICCs)** provide advice and assistance to their respective local lead agency and help to identify existing Early Intervention services and resources, to identify gaps in the service delivery system, and to develop local strategies to address those gaps. These Councils also assist the local lead agency to facilitate interagency agreements, support development of service coalitions, and establish local policies and procedures in accordance with federal and state laws and regulations.

**Referrals** to the Part C system can come from a variety of sources, including “self-referral” by a family. All families referred to Part C are eligible to receive a multidisciplinary evaluation and assessment to determine their children’s service eligibility. Referrals for evaluations and Part C services require the consent of the child’s parents or legal guardians.

The DMHMRSAS *Infant & Toddler Connection Annual Performance Report for FFY 2004* indicates that from 2001 to 2004, referrals for Part C came from the following sources: 57

percent from physicians, 11 percent from hospitals, 11 percent from friends and relatives, and 3–4 percent from social workers and preschool or day-care sources. The more recent *System of Payments Summary Report* by Solutions Consulting Group, in comparing referral data over time, found that in FY 2006: physician referrals decreased to 39 percent of all referrals; hospital referrals increased slightly to 12 percent; referrals from parents and guardians more than doubled to 23 percent; and referrals from friends, neighbors, and relatives decreased to approximately 3 percent.

Data on the unduplicated number of infants and toddlers receiving services under Part C is calculated annually in two ways: as a count at a point-in-time (December 1st), referred to as the “December Child Count”; and as a total number served during the year, referred to as the “Annualized Count” (previously known as the Aggregate Count). It is important to know that the December Child Count does not reflect all children served throughout the year. Each December 1st, the **Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)** tallies the number of individuals served by Part C services on that day.

The table below depicts the number of infants and toddlers receiving Part C services over the time period of 2002–2006 as determined by each counting method. It must be pointed out that the December Counts for 2003 and 2004 shown below differ from the data reported in the Board’s 2006 *Biennial Assessment of the Disability Services System*, which were taken from the DMHMRSAS 2005 *Report on Virginia’s Part C Early Intervention System*. The DMHMRSAS Part C staff reports that the figures below, excerpted from the more recent *System of Payments Summary Report*, are the correct figures and that there have been problems with obtaining an accurate child count, with discrepancies of up to 1,000 children improperly or not at all accounted for in past years. The DMHMRSAS staff noted that moving the Part C data system in-house rather than (as in past years) using an external contractor will provide improved accountability and accuracy. The following data represent the corrected December 1 Child Count Figures and Annualized Count through 2006.

#### NUMBER OF INFANTS AND TODDLERS RECEIVING PART C SERVICES

<u>Type of Count</u>	<u>2002</u>	<u>2003</u>	<u>2004</u>	<u>2005</u>	<u>2006</u>
<b>December 1st Child Count</b>	4,163	4,204	4,415	4,335	4,619
<b><u>Annualized Count</u></b>	7,409	8,052	8,661	9,209	10,704

\*Source: *System of Payment Summary Report: Solutions Consulting Group, 2007.*

More recent data are available from the *Report on Virginia’s Part C Early Intervention System* (Budget Item 312 K.2, 2006), which was released in October 2007. According to this report, the number of children receiving Part C services in state fiscal year (FY) 2007 (i.e., between July 1, 2006, and June 30, 2007) was 10,330, representing a 12 percent increase over those served the previous fiscal year. If data from the *System of Summary Payments Report* for FY 2006 is correct, however, then this percentage increase is not pointing to continued data and reporting inconsistencies. These data discrepancies, which may be attributed in part to calendar versus fiscal year reporting, demonstrate reporting-format inconsistencies that are problematic to

conducting accurate analyses. DMHMRAS clearly acknowledges this issue and is putting forth extensive effort to improve Part C data collection and reporting.

Virginia lags behind other states in identification of infants and toddlers who may have a developmental delay or a disability that is likely to result in a developmental delay and who are in need of services. The table below depicts data found in the draft *Part C State Annual Program Performance Report for FFY 2006*, developed by DMHMRSAS. Based on the December 1, 2006, Child Count, 0.53 percent of infants and toddlers (birth to 1) were served in the Virginia Part C system. This DMHMRSAS report noted that “as a group, states with broad eligibility similar to Virginia were serving 1.22% of the birth–1 population in 2006. National data for December 1, 2006 indicated 1.04% of the birth–1 population was receiving Part C services nationally.”

**COMPARISON OF VIRGINIA AND OTHER STATES:  
PROPORTION OF INFANTS AND TODDLERS SERVED BY PART C**

AGE GROUP	Percentage of Population Served			
	Dec. 1, 2005		Dec. 1, 2006	
	Virginia	States with Similar Eligibility	Virginia	States with Similar Eligibility
<b>Birth to Age 1</b>	0.51%	1.03%	0.53%	1.22%
<b>Birth to Age 3</b>	1.72%	2.22%	1.78%	2.75%

\*Source: DMHMRSAS: Draft *FFY 2006 Part C State Annual Program Performance Report; Part C State Annual Program Performance Report for FFY 05*.

As the data indicate, similar differences are apparent for children in the larger age cohort of birth to age 3. Based on the December 1, 2006, Child Count, Virginia served 1.78 percent of infants and toddlers birth–3 through Part C. This proportion was slightly higher than the 1.72 percent enrolled at the same point-in-time in 2005. The draft *Part C State Annual Performance Report for FFY 2006* states that “as a group, states with broad eligibility criteria similar to Virginia’s were serving 2.75 percent of the birth to three populations in 2006.” This percentage was an increase from 2005, at which time these states served 2.22 percent of that population. National data for all Part C systems for December 1, 2005, indicated 2.34 percent of the birth–3 population was receiving Part C services nationally vs. 2.43 percent in 2006. Thus it appears that while Virginia continues to make strides, the percentage of children served continues to be lower than other states with similar eligibility criteria and is also behind national levels.

According to the *System of Payments Summary Report*, the average age of referral of infants and toddlers to the Part C system remained static at about 16 months from 2000 through 2006. The average age at time of referral ranged from 13.06 months to 18.97 months. The authors noted that the data indicate “serious problems for the Commonwealth as a whole in locating and identifying children < 12 months.” They note that data on the average age of referrals indicate that a majority of children in the Part C system are served for less than 8.5 months before having to exit from the system.

## D. What Early Intervention Services Are Available?

Virginia's Part C Early Intervention services are based on current research and best practices that emphasize empowering parents and strengthening their abilities to meet the developmental needs of their children, encouraging consistency of intervention, and avoiding overutilization of therapy. Parents and service providers become partners, working closely together to make the most effective use of learning opportunities and other activities that arise normally throughout their child's and their family's daily routine. Frequency, structure, and level of services are designed to fit each individual family's schedule, environment, and needs for support.

The **Individualized Family Services Plans (IFSP)** and subsequent follow-up emphasize a holistic and seamless approach that brings together additional medical, developmental, psychosocial, and educational resources to ensure that the comprehensive needs of the child and family are met most effectively. Frequency and intensity of IFSP activities are adjusted as the child's and family's need for support and guidance changes. Individual components of an IFSP may include:

Assistive technology	Psychological services
Audiology	Respite care
Family training, counseling, and home visits	Social work services
Health services	Specialized instruction
Medical diagnostic and evaluation services	Speech/language pathology
Nursing and nutrition services	Transportation
Vision services	Occupational therapy
Physical therapy	

In order to increase family participation in their children's therapies and to provide continuity and consistency in service delivery, federal regulations stipulate that Early Intervention services must be provided in "**natural environments**" that meet the needs of the child to the maximum extent possible. Natural environments are defined as the home and other community settings that include children without disabilities and that are normal for the child's same-age peers. The provision of services in other settings is deemed appropriate only if outcomes cannot be achieved in natural environments. The DMHMRSAS 2005 *Infant & Toddler Connection Performance Plan* reported that from 2002 to 2004, the proportion of children with IFSPs served under Part C services in natural settings improved significantly from 85 percent to 98 percent. In federal fiscal years (FFY) 2005 and FFY 2006, 99 percent of children were served in home- and community-based settings according to the respective *Part C State Annual Program Performance Reports* for those years.

A key component of an IFSP addresses a child's transition from services under the Part C Early Intervention portion of the Individuals with Disabilities Education Improvement Act (IDEA) to the Part B special education portion of that same act or to other community services, if needed. Family planning and preparation for transition from Part C to Part B services include training parents on timelines, future placement options, and other matters; transmission, with the

parents' consent, of information about the child to the local educational agency; and preparing the child to adjust to changes in service delivery. Federal regulations under IDEA require that states have policies and procedures on file with the U.S. Department of Education that ensure a smooth and effective transition between Part C programs and Part B preschool programs. Public schools must participate in transition planning with Part C local lead agencies, and an **Individualized Education Program (IEP)** must be developed and implemented for each child receiving Part C services before his or her third birthday if that child requires special education services under Part B.

The Part C system has improved significantly on this federal indicator. In FFY 2005, according to the *Part C State Annual Program Performance Report* for that year, DMHMRSAS set a target of 100 percent compliance. The state results for timely transition planning averaged 86 percent in the area of children provided IFSPs with transition steps and services; 89 percent for notification to the Local Education Agency (LEA, or local public school division) if the child was potentially eligible for Part B; and 87 percent for holding a transition conference. There were higher results in some localities. In FFY 2006, however, with the target remaining at 100 percent, results greatly improved: 96 percent of IFSPs included transition steps and services; notification to LEAs was sent to 93 percent of children potentially eligible for Part B; and transition conferences were held for 95 percent of children potentially eligible for Part B. This progress is to be commended. Local systems that were out of compliance with the indicators were required to develop a Corrective Action Plan/Service Enhancement Plan. State-level activities undertaken to improve performance on this indicator are described in the draft *Part C State Annual Program Performance Report for FFY 2006*.

In Virginia, a potential for overlap exists between the Part C Early Intervention and the Part B special education system for children ages 24 to 36 months. Since a child cannot receive Part C and Part B services concurrently, parents must decide whether the child will remain in the Early Intervention system during this period or will transition early to the special education system. Virginia is the only state that makes Part B services available to 2-year-olds, providing an important service delivery choice for families. Information on Part B special education eligibility services are covered in the Education chapter of this report.

## **E. Cost and Payment for Early Intervention Services**

This section provides information on the varied public-funding sources and expenditures for the Part C services system statewide. Following this information, a brief overview of health insurance resources, both private and public, available to families of children with disabilities will be provided.

**Part C System Funding and Costs:** As the state's lead agency, the **Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)** manages the budget of Virginia's Part C Early Intervention program. Children and families determined eligible for Part C services are entitled to receive those services. Not all Part C services are provided free of charge, however, and fees are charged in accordance with state law. Under

federal regulations 34 CFR 303.522 (a)(1) and 34 DFR 303.527, IDEA Part C Early Intervention funds may be expended only after other sources have been applied, such as public (Medicaid etc.) and private insurance, donations, and fees based on a family's ability to pay. According to public comment received by the Board and confirmed in the Solutions Consulting Group *System of Payments Summary Report*, wide variability in local contributions has resulted in some localities being unable to compete with local school divisions and other agencies for qualified providers, resulting in an overall shortage of and high turnover among qualified providers.

Each year, Virginia is allocated a specific amount from the federal government to support Part C services. Federal funds are allocated based on the state's proportion of the 0–3 population as compared to the national total. In Virginia, federal funds have remained relatively static. The majority of federal funds must be expended on direct services. The federal allocation for direct services for the last four years is as follows:

**PART C FEDERAL FUND ALLOCATIONS FOR DIRECT SERVICES**

<b>FY 2004</b>	<b>FY 2005</b>	<b>FY 2006</b>	<b>FY 2007</b>
\$8,900,000	\$8,900,000	\$8,419,704	\$8,839,815

Sources: DMHMRSAS: *Report on Virginia's Part C Early Intervention System* (Budget Item 312 K.2, 2006 Appropriations Act), *Report on Virginia's Part C Early Intervention System* (Budget Item 334 K, 2005 Appropriations Act), *Report on Virginia's Part C Early Intervention System* (Budget Item 334 K, 2004 Appropriations Act).

The total federal Part C allocations each year were higher than the federal allocation noted in the chart above, which represents the portion of the allocation for direct services only; the portion of the allocations not used for direct services are expended for state and local infrastructure costs. In FY 2005, the total federal allocation for Part C was \$10,820,066; in FY 2006 it was \$10,127,614; the FY 2007 allocation was \$10,269,886.

An additional amount is allocated by the state legislature from general funds, and while they are not required to, many localities contribute both cash and in-kind support for Part C services. Local contributors include, among others, community service boards, health departments, and schools as well as the Part C local lead agencies themselves.

Determining exactly how much of total Part C funding is derived from federal, state, local, and fee-based sources has historically been very difficult. This was acknowledged by DMHMRSAS in its October 2005 *Report on Virginia's Part C Early Intervention System* to the Virginia General Assembly (Budget Item 334K, 2004 Appropriations Act). This report noted that

currently there is no easy mechanism to link child data with either the Office of Special Education Programs (OSEP) required data elements, monitoring data, and family survey data that is collected to meet the legislative reporting requirements. ... Starting in fiscal year 2007, the Department will have access to accurate data that will reflect current service utilization and revenue data of children in the system.

A great deal of progress has been made in expanding state funding for Part C services in Virginia. As noted in the October 1, 2007, *Report on Virginia's Part C Early Intervention System* (Budget Item 312 K.2) the General Assembly significantly increased general fund appropriations for Part C services as a result of the 2004 *Virginia Cost Study Report* by Solutions Consulting Group. Based on the *Cost Study Report* findings regarding the projected number of eligible children and the average annual cost per child for Early Intervention services (\$4,148 for FY 2002–2003), the General Assembly adopted Budget Item 334K and significantly increased the allocation of state general funds for Early Intervention services. All state general fund appropriations for Part C services are required to be used for direct services. Allocations by state fiscal year are shown in the figures below.

#### PART C STATE GENERAL FUND ALLOCATIONS

<u>FY 2003</u>	<u>FY 2004</u>	<u>FY 2005</u>	<u>FY 2006</u>	<u>FY 2007</u>	<u>FY 2008</u>
\$125,000	\$975,000	\$3,125,000	\$3,125,000	\$7,203,366	\$7,203,366

\*Source: DMHMRSAS: Report on Virginia's Part C Early Intervention System (Budget Item 312 K.2, 2006 Appropriations Act).

A review of the numbers of infants and toddlers served by the Part C system and related state spending finds a significant lack of proportion between the two. Between Fiscal Years 2003 and 2006, the annualized, unduplicated count of children served rose from 8,052 to 10,704, an increase of 33 percent. The annual December 1 census of children being served by the system on a single day showed a more modest increase of 9.8 percent, from 4,204 in 2003 to 4,619 in 2006. In contrast, spending for the same period grew 24-fold (2,400 percent), from \$125,000 to more than \$3.1 million.

While not included in the table entitled **Number of Infants and Toddlers Receiving Part C Services** because it came from different source material (the data disparity discussed earlier), the DMHMRSAS *Report on Virginia's Part C Early Intervention System to the Governor and General Assembly* (Budget Item 312 K.2) notes that the annualized count of children for FY 2007 was 10,330. This is fairly stable from the previous year. Funding between FY 2006 and FY 2007, however, doubled, resulting in a 57-fold (5,600 percent) increase in state funding from the lowest level in FY 2003 to its current level in FY 2007 and FY 2008.

The disproportionate growth in state funding compared to numbers served could stem from higher costs for serving children in natural environments, including additional transportation costs; a higher intensity of services required for children with more significant disabilities, such as autism (noted in the 2006 *Biennial Assessment*); lower local contributions toward the total cost of Part C services as state funding has increased; or other causes still to be determined. DMHMRSAS staff members, who track this data, recognize and support the need for further review of Part C expenditures that would include an assessment of whether sufficient funds are being directed to Child Find efforts.

In a presentation before the Virginia Interagency Coordinating Council on September 12, 2007, the authors of the *System of Payments Summary Report*, Solutions Consulting Group, stated: “The infusion of new state funds has had little impact on the number of children in service using the point in time count. The 2005 number actually represents a small drop with the 2006 increase slightly more than the change in 2004.”

An annual accounting of Part C funds is required. To accomplish this, DMHMRSAS has incorporated additional reporting elements into the local lead agency contract to ensure the ability to account for revenues and expenses. A number of challenges were cited with respect to required data reporting, however. The DMHMRSAS October 2007 *Report on Virginia’s Part C Early Intervention System* (Budget Item 312 K.2) cites the following challenges:

- “No systemic collection of data regarding planned service levels,
- “No systemic cost information captured,
- “No systemic delivered service information, and
- “No central listing of service providers.”

To address these issues, the Department completed an analysis of its data system and all federal and state reporting requirements. The October 2007 *Report on Virginia’s Part C Early Intervention System to the Governor and General Assembly* (Budget Item 312 K.2) notes that the revamped accountability system would be phased in with the first step being transfer of the data collection system into DMHMRSAS (as opposed to contracting out for this service). This transfer occurred in February 2007. The Department reported that improvements are already underway with respect to more accurate reporting. The table below shows FY 2007 state and federal revenue for Part C from all sources as reported by the 40 local lead agencies.

#### AMOUNT AND SOURCE OF REVENUES FOR PART C, FY 2007

<b>Part C Revenue Source</b>	<b>FY 07 Revenue</b>
	<b>Amount</b>
<b>Federal Part C Funds</b>	\$ 8,839,815
<b>State Part C Funds</b>	7,203,365
<b>Local Funds</b>	7,427,535
<b>Family Fees</b>	367,346
<b>Medicaid</b>	1,081,489
<b>Targeted Case Management</b>	971,609
<b>Private Insurance</b>	825,931
<b>Grants/Gifts/Donations</b>	304,412
<b>Other</b>	1,008,074
<b>Local report of aggregated non-Part C Revenue</b>	<b>2,623,750</b>
<b>TOTAL</b>	<b>\$30,653,326</b>

\*Source: DMHMRSAS: *Report on Virginia’s Part C Early Intervention System to the Governor and General Assembly*: (Budget Item 312 K.2).

DMHMRSAS noted in its report that seven local lead agencies were not able to report revenue by category but did report an aggregated amount of non-Part C revenue used to support local Part C services. It was also noted that revenue reporting from private providers was optional in 2007 because of data system challenges and the burden that private providers would have had with respect to manual data collection. DMHMRSAS reports that it expects to have “accurate and complete revenue data from all providers, including private providers through the enhanced Part C data system no later than fiscal year 2010.”

This October 2007 report also summarized expenditures for Part C services for federal fiscal year (FFY) 2007 (October 1, 2006–September 30, 2007). The report notes that the local lead agencies (number of agencies not specified) reported an additional \$15,986,056 of aggregated expenses that were not able to be reported by category.

**PART C DIRECT SERVICE EXPENDITURES BY CATEGORY FOR FFYs 2005 AND 2007  
(FEDERAL AND STATE FUNDS)**

<b>Expenditure Category</b>	<b>FFY 2005*</b>	<b>FFY 2007**</b>
<b>Assistive Technology</b>	\$ 24,083	\$ 34,629
<b>Audiology</b>	46,750	12,691
<b>Evaluation and Assessment</b>	31,875	840,445
<b>Family training, counseling, home visits</b>	809	50,097
<b>Health</b>	1,822	3,290
<b>Nursing</b>	3,238	1,559
<b>Nutrition</b>	17,810	1,733
<b>Occupational therapy</b>	1,023,037	903,419
<b>Physical therapy</b>	1,916,753	1,623,660
<b>Psychology</b>	10,524	1,500
<b>Service coordination</b>	3,970,722	4,238,341
<b>Social work</b>	22,970	62,567
<b>Special instruction</b>	1,168,043	1,810,959
<b>Speech language pathology</b>	2,784,564	2,195,039
<b>Transportation</b>	13,357	68,906
<b>Vision</b>	39,869	42,627
<b>Other Entitled Part C Services</b>	48,774	403,555
<b>Lead Agency Operations and Support</b>	1,000,000	Not Included
<b>Total Direct Services</b>	<b>\$12,124,970</b>	<b>\$12,295,057</b>

\*Source: DMHMRSAS: *Report on Part C Early Intervention System* (Budget Item 334K), October 2005.

\*\*Source: DMHMRSAS: *Report on Virginia's Part C Early Intervention System* (Budget Item 312K.2), October 2006.

In reviewing the expenditure data, there are significant differences in expenditures in certain categories between FFY 2005 and FFY 2007. Although generalized conclusions cannot be drawn, the DMHMRSAS report does note that the enhanced data system allowed reporting of the actual number of initial assessments and evaluations conducted. Other than that example, it is unclear whether there have been true differences in spending trends or the differences are just representative of the ongoing challenges with expenditure tracking cited earlier.

The 2007 *System of Payments Summary Report* observed that there is greater collaboration by state Part C systems on a national level in implementation and resources available for payment than in Virginia. This report also notes that the Commonwealth is “uniquely poised to maximize ... partnerships and provide expanded services and supports to eligible infants and toddlers through early identification, prevention and early intervention services.” Not unexpectedly, however, the report found that the state continues to face financial and programmatic challenges, some of which already have been described in this chapter. The following findings are excerpted from the *System of Payments Summary Report* but are not all-inclusive of the many report findings.

- There is a “lack of consistency and uniformity in application of Ability to Pay (ATP),” which results in: (a) families declining services they would have to pay for; (b) localities having variable procedures for documenting ATP; (c) and DMHMRSAS being unable to ensure that services are not withheld or withdrawn from families because of their inability to pay, noted by the consultants to be a serious compliance issue. Issues affecting the ATP system are complex and addressed in detail in the consultants’ report. The following statements demonstrate the severity of the problem: “Central to the issues identified is that there is no reporting mechanism used to collect information from providers about these family payments or third party reimbursements. Consequently, there is no statewide data on delivered services or the total funds/resources supporting the Part C system.”
- “DMHMRSAS has limited ability to ensure and demonstrate to the OSEP [Office of Special Education Programs] that Payor of Last Resort federal requirements are implemented statewide.”
- The system lacks timely and accessible reimbursement for providers, and “third party billing is often cumbersome and expensive.”
- “There is inadequate evidence to support non-supplanting/maintenance of effort requirements.” According to the consultants, “DMHMRSAS has no data or ability to document that they have identified and are coordinating resources at all levels” and “no

data or ability to demonstrate to OSEP that Part C funds are not being used to replace current resource such as CSB or other local funds.”

- DMHMRSAS does not have a standard procedure for replacement of a local lead agency if that agency is no longer able or willing to carry out this responsibility. This situation occurred within the last biennium, and the state had to carry out local functions until a new lead agency could be designated.
- There are issues regarding those children whose families choose only to receive service coordination (case management) but who have elected to receive all other services outside of the publicly funded system. There is currently no federal standard for whether the children constitute a “child being served” under the Part C system. The consultants noted that DMHMRSAS needs to determine why these families have declined Part C services, a decision that leaves them no procedural safeguards or protections.

The *System of Payments Summary Report* specifically identified issues to be considered in planning system improvements related to financing. These include age/lifespan considerations, diagnosis of disability, income, degree or level of support needed, type of service or support, and special population needs. The consultants recommended that distribution of funds by the lead agency be proportionately allocated based on a combination of demographics and consideration of third-party resources (including Medicaid, private insurance, and family fees), and that measures should be incorporated to encourage local contributions that promote utilization of all resource opportunities.

At a November 8, 2007, Part C Medicaid Stakeholder workgroup, a Solutions Consulting Group representative presented the recommendation that Virginia establish an amendment to the Medicaid State Plan to include Part C as a covered service for infants and toddlers who have an Individualized Family Services Plan. The State Plan Amendment would be the only vehicle for accessing Part C services through Medicaid; and Part C services could not be accessed under other chapters of Medicaid or through home and community-based waivers. The consultants set forth the manner in which screening, evaluation and assessment, case management, claims, and service delivery would take place as well as the key implications of a decision to take this action. At the time of publication of this report, no decisions had been made on the recommendation.

**Public Health Insurance:** For many families of children with disabilities, public health insurance is a critical benefit that provides access to needed services. Basic information on eligibility, coverage, and administration under Virginia’s public health insurance plans can be found in the Health chapter of this report.

Of particular relevance to Part C services is the state's **Medicaid FAMIS Plus** program, which provides coverage for **early and periodic screening, diagnosis, and treatment (EPSDT)** for children determined to be Medicaid eligible. EPSDT services are intended to help ensure that a child's health problems are diagnosed and treated early before they become more complex and their treatment more costly. EPSDT provides comprehensive coverage including assessment/diagnosis and the medically necessary services that are required to correct the identified condition, ameliorate their effects, prevent them from worsening, or prevent the development of secondary conditions. EPSDT is an important funding source for Part C services. Medicaid eligibility for children who are receiving services from a Home and Community Based Waiver such as the MR, DD, or EDCD Waiver is based solely on the children's income and assets, regardless of parental income and assets. Thus, they are entitled to all of the services available through EPSDT.

Families not eligible for Medicaid FAMIS Plus may qualify for coverage under the State's Children Health Insurance Program (CHIP), which in Virginia is known as the **Family Access to Medical Insurance Security (FAMIS)** program. Coverage under this plan, however, may not be as comprehensive as coverage provided through FAMIS Plus.

Medical services covered by each of these plans varies, but generally they include well-baby checkups, doctor visits, vaccinations, prescription drugs, laboratory tests, X rays, hospitalizations, and emergency care. Dental, vision, and mental health services are also included as are speech/language, physical, and occupational therapies and appropriate durable medical equipment. Nursing and personal assistant services may also be covered. While some services are covered in full, others may require co-payments.

In the *2006 Biennial Assessment*, Medicaid reimbursements for specialized services for infants and toddlers ages 0–3 were reported for the categories of rehabilitation, audiology, psychological services, nursing services, and all other services. The total FY 2005 expenditures under Medicaid were reported to be \$52,441,692. Because of complications with the reliability of the data, expenditures for FY 2007 could not be obtained prior to the printing of this report.

**Private Health Insurance:** In July 1997, coverage of Early Intervention services became a required part of the state's employee health insurance program (*Code of Virginia*, § 2.2-2818). In July 1998, that mandate, which requires coverage up to an annual limit of \$5,000 per insured child, was extended to Virginia-regulated accident and sickness insurance policies providing coverage to private companies operating in the state (*Code of Virginia*, § 38.2-3418.5). Self-insured companies were exempted from this requirement, but some have elected to include this benefit. The *2004 Virginia Cost Study* estimated that 12.08 percent of revenues for Part C services were provided by these private insurance sources. In FY 2007, only 3 percent of revenues were provided by private insurance sources.

## F. Monitoring and Evaluation of Early Intervention Services

Each state receiving federal financial assistance under Part C of the Individuals with Disabilities Education Improvement Act (IDEA) is required to establish an advisory interagency coordinating council to support the lead state agency and other agencies providing and paying for Part C services. The **Virginia Interagency Coordinating Council (VICC)** fulfills this requirement by providing guidance on the implementation and evaluation of the statewide Early Intervention system, including the transition of toddlers with disabilities to preschool and other appropriate services. VICC membership includes: parents, public, or private providers of Early Intervention services, state agency representatives, a legislator, and an individual involved in the preparation of personnel engaged in Early Intervention services.

Virginia law requires the **Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)** to monitor all state and local public and private agencies and providers of Early Intervention services, regardless of whether or not those services are funded by IDEA Part C. To ensure compliance with state and federal laws and regulations, all public and private Early Intervention service providers must agree to comply with Part C requirements in writing through an interagency agreement, memorandum of understanding, or contract. The most recent description of Virginia's system of supervision and monitoring, including how data are gathered and verified, can be found in the draft *Part C State Annual Program Performance Report for FFY 2006*.

DMHMRSAS continues to work closely with its local partners to improve the Part C program and services to infants and toddlers throughout the state. As noted earlier and discussed throughout the chapter, DMHMRSAS contracted with Solutions Consulting Group to assess strengths and weaknesses of Part C Early Intervention services. The initial objective of the study was to focus on the Ability to Pay (ATP) system for Part C. After consultation with this contractor early in 2006, the scope of work was expanded to examine the entire Part C system of Payments and other programmatic issues.

An important statistic tracked for Part C is the proportion of children who were **referred for but did not receive services** (or did not move on to receipt of services). This was identified as a challenge by DMHMRSAS in its *Part C State Annual Program Performance Report for FFY 2005* as well as by Solutions Consulting Group. The *System of Payment Summary Report* notes that of all 9,779 referrals made in FY 2006, 45 percent did not move on to receipt of Part C services. The variety of reasons included, but were not limited to: death of the child; parents declined screening or evaluation; the child was found eligible, but the family either chose other services or declined services; the child was found eligible, but could not be contacted or located; or the child was found ineligible for services. As the report pointed out, examining the high percentage of children referred but not moving to services is important because of the high costs to the system both in terms of clinical and family time as well as monetary resources.

This report also identified that the highest proportion of children who were referred but did not move on to service (other than those referred by a friend, neighbor or relative) were

referred by the Virginia Department of Social Services (DSS). Four localities had the most referrals of children to Part C services in FY 2006: Fairfax–Falls Church, Virginia Beach, Hampton–Newport News, and Chesterfield County. The proportion of children referred that did not move to services were as follows for each locality: 35.2 percent, Fairfax–Falls Church; 59.5 percent, Virginia Beach; 61.4 percent, Hampton–Newport News; and 14.4 percent, Chesterfield County, which had the lowest percentage of all localities reporting more than 200 referrals.

DMHMRSAS, citing the same statistics in its draft *Part C State Annual Program Performance Report for FFY 2006*, noted that the percentage of infants and toddlers who were referred but did not enter Part C services had increased from 25 percent of all referrals during 2002–2004 to 30 percent in 2005.

The *System of Payments Summary Report* recommended that two issues be studied further: (1) the low number of DSS referrals in light of Child Find requirements, and (2) an apparent lack of understanding of Part C eligibility requirements as reflected by the overall total of 45 percent of DSS referrals' not moving on to service. Solutions Consulting Group advised that the Part C system needs to improve services in two ways:

1. Increase the identification of children at younger ages (i.e., less than 12 months), and
2. Increase the percentage of children referred who actually go on to receive services.

DMHMRSAS cited additional challenges in its *Part C State Annual Program Performance Report for Federal Fiscal Year (FFY) 2005*. Among these were the following:

- Anecdotal evidence (as cited by DMHMRSAS) indicates that private providers are marketing their services for infants and toddlers and that more families are choosing services outside of the Part C system.
- Many staff members in the new Medicaid managed-care organizations have no knowledge about the supports and services available through Part C and do not know how to make a referral for these services and supports. Instead, the managed care service providers are making direct referrals to therapists outside the Part C system.
- Local Part C systems report that hospitals are delaying referrals to the Part C system until insurance runs out for therapy through hospital clinics and providers.
- Shifts in cultural groups have not been followed with shifts in public awareness and Child Find strategies.
- Children without a “medical home” do not have a primary mechanism for referral.

The *Part C State Annual Program Performance Report for FFY 2005* and the draft *Part C State Annual Program Performance Report for FFY 2006* also provide information on important progress made in a variety of areas, including the addressing the challenges of

reaching all eligible children. Positive developments and improvement activities reported by DMHMRSAS included, but were not limited to, the following:

- Continued implementation of a statewide public awareness campaign, including children's cups advertising the program, bus placards, and public service announcements.
- A variety of presentations and in-service trainings to state and local agency staff members and private providers.
- Dissemination of the Infant and Toddler Connect Update and improved Web site.
- Revised policies for better identifying children from under-represented areas.
- Technical assistance on establishing and maintaining communication with primary referral sources.
- Locating entrance points for underserved and various cultural populations.
- Analyzing referral information and eligibility determinations by referral sources.
- Expanding interagency collaboration in public awareness and Child Find, and revising interagency agreements and provider contracts.
- Implementation of competency testing for Part C personnel.

Other activities in development or underway designed to increase the number of children referred and receiving services are described in detail in the draft *Part C State Annual Program Performance Report for FFY 2006*.

There have also been a number of positive outcomes resulting from DMHMRSAS oversight activities that have occurred within the last several years. Some of those outcomes are detailed below.

**Outcomes from 2003 Infrastructure Task Force:** In a major initiative to address Part C concerns, DMHMRSAS in 2003 convened a group of stakeholders to examine the system, identify its strengths and challenges, and make recommendations for infrastructure changes that would improve the system. The Infrastructure Task Force reviewed administrative, funding, and service delivery issues and identified a number of challenges facing the system as well as recommendations to address these challenges. The challenges brought forward through this Task Force (described in more detail in the *2006 Biennial Assessment of the Disability Services System*) predominantly focused on issues of growth in the number of children being served and insufficient financial resources to do so, and inconsistency in local implementation of Part C requirements policies and procedures, and unenforceable contracts. The Infrastructure Task Force made a number of recommendations to the DMHMRSAS Commissioner in July 2004 to address these challenges.

The *Part C State Annual Program Performance Report for FFY 2005* reported the changes that were made on the basis of the Part C Task Force recommendations. Among these changes were the following:

- Local contracts were modified and the role of local interagency coordinating councils was shifted to serve as advisors to the local lead agency (similar to the role that the Virginia Interagency Coordinating Council [VICC] serves to the state lead agency, DMHMRSAS).
- The legal authority for DMHMRSAS and local lead agencies to enter into contracts was established, and local lead agencies were identified that could accept Part C funds, contract or otherwise arrange for services with local providers, assure compliance with fiscal and programmatic regulations and policies, and provide necessary reports on local activities to DMHMRSAS.
- Local Council Coordinators were renamed Local System Managers better to reflect their responsibilities.
- The local fiscal agent and the local lead agency are now required to be the same entity.

**Dispute Resolution:** Unlike in the IDEA Part B special education system, formal complaints in the Part C system are rare. The draft *Part C State Annual Program Performance Report for FFY 2006* notes that no due process hearing or mediation requests were received in FFY 2006; two complaints were received, but both were withdrawn. According to the *Part C State Annual Program Performance Report for FFY 2005*, since 1994, only thirteen written, signed complaints have been received, with eight withdrawn and only one request for due process with this request resolved informally and withdrawn. Mediation has been requested twice and both instances resulted in signed mediation agreements.

In its FFY 2005–2010 *Part C State Performance Plan*, DMHMRSAS reported that it would develop a dispute resolution handbook. The handbook, not yet complete at the time of the Board's report, is set to contain information regarding administrative complaints, mediation, and due process hearings for use by service providers and families; and a mechanism to collect data on the number of potential complaints that are resolved informally through the efforts of the Part C Office of Family Involvement project.

**Office of Special Education Monitoring:** In 2005, the U.S. Department of Education's Office of Special Education Programs (OSEP) conducted a compliance site visit for Virginia's Part C services system. The review focused on three areas: the data system, monitoring and supervision, and the complaint process. OSEP sought to determine if information collected and reported by the state is reliable, credible, and accurate as well as to what extent it is used to make policy decisions and to ensure compliance with federal regulations. The findings (reported in greater detail in the *2006 Biennial Assessment of the Disability Services System*) included, but were not limited to, the following:

- Data submitted by local provider systems need to be verified; the state needs to require that the local lead agency implement procedures to review data accuracy or certify the accuracy of its data.
- The system needs to verify that families are receiving all services included in their Individualized Family Services Plans.
- The Infant & Toddler On-Line Tracking System reports only those services initially planned, not those actually received.
- Weaknesses in the online tracking system affect Virginia's ability accurately and completely to meet federal data reporting requirements. For example, the state has had no way to determine the extent of inaccurate data or data-entry errors. In addition, the data entered are from the initial Individualized Family Services Plans (IFSP) and not, as required by law, from the child's most recent IFSP.

In its April 2005 Verification Visit follow-up letter to the DMHMRSAS Commissioner, OSEP acknowledged Virginia's efforts to improve accountability and compliance monitoring. The letter also cited several other areas that needed improvement as follows:

- Virginia's monitoring reports do not specify areas of noncompliance that the local lead agency must correct.
- There is no formal process for approving local improvement plans and no systematic procedures for determining whether a local lead agency has corrected noncompliance.
- The Commonwealth has never imposed sanctions if a local lead agency did not correct noncompliance.

DMHMRSAS submitted a plan of improvement to address these issues and has been engaged in the process of correcting them through data system improvements and a new data verification process. A key data system improvement described in the *Part C State Performance Plan for 2005–2010* was development of a master plan for technology solutions, completed in March 2006. In April 2006 local systems began using new reports that review and confirm in writing the accuracy of the local data (by the local system manager). It was reported that by January 2008 the data system will be enhanced to require that services and setting data (where children receive services) be updated for each child at the time of each IFSP review and annual IFSP. Additional information on data collection and reporting improvements can be found in the *Part C State Performance Plan for 2005–2010*.

Additional progress was noted by DMHMRSAS in its February 2007 *Part C State Performance Plan Update* to the OSEP. Among the improvement activities it reported having undertaken were:

- Development and implementation of procedures to ensure that all monitoring reports resulting from any state-monitoring activities specify any areas of noncompliance that the local agency must correct as well as the required timelines for correction.

- Development and implementation of procedures to ensure that all local plans of improvement are approved by the Part C Office prior to local implementation of the plan.
- Establishment of effective sanctions and use, when necessary, to correct local noncompliance that exists for more than one year. A range of sanctions was established in April 2006 along with a system to evaluate the effectiveness of these sanctions. The potential for sanctions was formally included in the SFY 2007 *Local Contract for Continuing Participation in Part C*. In addition DMHMRSAS continues to explore potential incentives for localities to achieve and maintain compliance.
- Development and implementation of procedures for the Part C Office by which to determine for every lead agency with a plan of improvement whether noncompliance has been corrected no later than one year after approval of the training plan by the Part C Office.
- Additional activities, which occurred from January to July 2007, included continued training and technical assistance, revised format and reporting processes, and site visits. In addition, the Part C budget includes funds for hiring additional Part C–monitoring staff members at DMHMRSAS.

**Child Find:** Child Find activities have been targeted as an area of focus for monitoring and improvement for several years. According to the draft *Part C State Annual Program Report for FFY 2006*, in that year 19 local systems were required to develop corrective action plans on this indicator. In addition, a stakeholder group was formed to review and revise Ability to Pay policies to ensure that these were not a barrier to seeking or accepting Part C services. The 2007 *Systems of Payments Summary* report noted that, among the forty Part C local systems, 16 were in compliance with the 2006 state target of serving 0.65 percent of infants and toddlers (still well below the national average), and an additional 2 local systems were in substantial compliance. A variety of improvement activities are reported to be underway by DMHMRSAS to improve the performance of the 22 local systems in noncompliance with the state target. The DMHMRSAS anticipates that it will take some time to show results from these efforts and to determine the specific factors that have an impact on how localities implement Child Find and the Ability to Pay system.

Statewide, a variety of local improvement strategies have been implemented in order to increase the number of infants and toddlers being served and to improve compliance with Child Find targets. As noted in the draft *Part C Annual Program Performance Report for FFY 2006*, these included, but are not limited to:

- Improving relationships with hospital contacts and with Care Connection of Virginia and maintaining ongoing communication with those contacts.
- Implementing a “Guide by your Side” program that matches the trained parent of a child with hearing loss to families of newly diagnosed children.
- Creating a Web site that provides doctors and nurses with information about the Part C system and referral procedure information.
- Conducting meetings and training with hospital Neonatal Intensive Care Unit (NICU) discharge planners to review referral procedures and to determine follow-up for children referred and found to be initially ineligible.
- Including 115,000 copies of the Part C developmental checklist in New Parent Kits distributed by local departments of social services and other agencies.
- Expanding local marketing and outreach activities such as participating in baby fairs, mall/store events, and other community-sponsored events that target infants; providing brochures in packets for new moms and in boxes of diapers; and providing information at childbirth classes.
- Working with Early Head Start to identify children on the waiting list who are birth to 1 who have not been screened for development.

In its June 2007 letter to DMHMRSAS, the federal Office of Special Education Programs (OSEP) responded to the progress report/State Performance Plan submitted in February 2007 and determined the federal performance “category” under which Virginia falls. Categories for Part C determinations include “meets requirements” (17 states/territories were in this category); “needs assistance” (25 states/territories were in this category); “needs intervention” (16 states/territories were in this category); and “needs substantial intervention” (no states/territories were in this category). In making a determination, OSEP reviewed the *Part C State Annual Program Report for FFY 2005*, the revised State Performance Plan, other state-reported data, and information obtained through monitoring visits and other public information. OSEP determined that Virginia fell within the “needs assistance” category.

OSEP noted that various performance indicators found in Virginia’s *Part C State Performance Plan* and the *Part C State Annual Performance Report for FFY 2005: Response Table* were problematic. (The reporting period for data was 10/1/04–9/30/05.) Of note, however, are the significant improvements in these indicators as reported in the draft *Part C State Annual Program Performance Report for FFY 2006*. The table below compares the performance outcomes for both federal fiscal years.

**COMPARISON OF ACTUAL RESULTS ON OSEP PERFORMANCE INDICATORS,  
FFYS 2005 AND 2007\***

<b>Performance Indicators</b>		<b>FFY 05</b>	<b>FFY 05</b>	<b>FFY 06</b>
<b>#</b>	<b>Description</b>	<b>Target</b>	<b>Results</b>	<b>Results</b>
<b>1</b>	Percent of infants and toddlers who receive early intervention services on their Individualized Family Service Plans (IFSPs) in a timely manner	100%	72%	81%
<b>8</b>	Percent of all children exiting Part C who receive timely transition planning to support the transition to preschool and other appropriate services by their 3rd birthday, including:			
<b>8-A</b>	IFSPs with transition steps and services	100%	86%	96%
<b>8-B</b>	Notification to LEA if child is potentially eligible for Part B	100%	81%	93%
<b>8-C</b>	Transition Conference, if child is potentially eligible for Part B	100%	51%	95%
<b>9</b>	Noncompliance corrected as soon as possible but in no case later than one year from identification	100%	75%	95%

\*Source: Data for FFY 2005 are from the *Part C State Performance Plan/FFY 2005 Annual Performance Report Response Table*. Data for FFY 2006 are from the draft *FFY 06 Part C State Annual Program Performance Plan*.

OSEP cited a high level of compliance in FFY 2005 for a number of performance indicators, which included the following. Results from FFY 2006, as above, are included for comparison.

- Indicator 2, Percent of infants and toddlers with IFSPs who primarily receive Early Intervention services in the home or community: Actual state results in FFY 2005 were 99 percent, with the target being 98.425 percent. A 99 percent result was maintained in FFY 2006. This is significant, since services in the natural environment had been an area of noncompliance in an earlier OSEP-monitoring site visit.
- Indicator 7, Percent of eligible infants and toddlers with IFSPs for whom an evaluation and assessment and an initial IFSP were conducted within Part C 45-day timeline: Actual state results in FFY 2005 were 98 percent, with the target being 100 percent. (This was an improvement over the result of 93 percent compliance for the period 1/1/05–6/30/05.) State results for FFY 2006 were 96 percent compliance, slightly down from FFY 2005. DMHMRSAS reports that this is caused by one local system that had personnel shortages.

Corrective actions taken to address areas on noncompliance or target shortfalls are described in the February 2007 *Part C State Performance Plan for 2005–2010* and the draft *Part C State Annual Program Performance Report for FFY 2006*. These activities include, but are not limited to: development of model documents, policy review, refinement of protocols and data collection, training, technical assistance, and focused monitoring of lowest performing systems. This document also details the number of local systems that were noncompliant or failed to reach targets in each specific area.

**System for Determination of Child Progress.** As noted earlier, efforts continue to improve data collection and accountability. As part of these efforts, Virginia has implemented the federally required *System for Determination of Child Progress*. The new system's implementation date was March 1, 2006; and in January and February of that year, 400 individuals attended eight provider training sessions on the system.

According to the *System for Determination of Child Progress* overview and implementation documents posted on the DMHMRSAS Web site, all children new to Early Intervention services who have an Individualized Family Services Plan (IFSP) on or after March 1, 2007, are included in the system. The data system includes rating a child's status on three indicators using a seven-point scale. The evaluation/assessment of the child occurs after entry and exit of the system, and is performed by the evaluation/IFSP team. The three indicators are:

1. Positive social emotional skills (including positive social relationships),
2. Acquisition and use of knowledge and skills (including early language and communication), and
3. Use of appropriate behaviors to meet needs.

Aggregated progress data for all children who exit the system during the reporting timeframe will be reported to OSEP in the *Part C State Annual Performance Report*. For each indicator and for every child enrolled, the following must be reported: the percent of infants and toddlers who:

- Did not improve functioning;
- Improved functioning, but not sufficient to move nearer to functioning comparable to same-age peers;
- Improved functioning to a level nearer to same-age peers but did not reach it;
- Improved functioning to reach a level comparable to same-age peers; and
- Maintained functioning at a level comparable to same-age peers.

An extensive training program was developed and delivered on this system. The training provided detailed information on how to assess each indicator in a functional and meaningful manner. Baseline data will be collected in state fiscal year 2008 (July 1, 2007–June 30, 2008); and performance will be measured in future years as compared to the baseline.

## **G. Areas of Concern for Early Intervention Services**

The chapter detail provides information on the breadth and depth of services available through the Part C system. Cited throughout the chapter are important statistical data regarding program activities and performance indicators. The chapter detail also provides information on

areas in which the system and services have improved and describes improvement activities and outcomes. Section G focuses on the specific areas in which further improvements may be needed to move the system forward and ensure that the needs of eligible infants and toddlers with disabilities throughout the Commonwealth are met. The Virginia Board for People with Disabilities (VBPD) identified the issues and concerns below through a variety of mechanisms, including: (1) review and analysis of the numerous source documents referenced within and listed at the end of this chapter, (2) public comment received via VBPD's six public forums held throughout the state in the spring of 2007, and (3) written comment and information provided and verified by state agencies in their reviews. The issues below are not all-inclusive, but represent those that VBPD has identified as important to systems improvement.

- 1. Impact of Increased Prevalence of Autism Diagnoses:** The increasing numbers of infants and toddlers being diagnosed as having autism spectrum disorder is creating pressure on Early Intervention and public school systems nationwide and worldwide. The increase in autism diagnoses is of such concern that in 2007 the American Academy of Pediatrics put forth a recommendation that the children be tested twice for signs of autism before their second birthday. Diagnoses are beginning to be made at an earlier age and the Part C system has long served infants and toddlers with autism or pervasive developmental delay, a diagnosis that sometimes predates a formal autism diagnosis. The rising incidence of autism has also brought forth challenges with respect to providing appropriate evidence-based interventions to infants and toddlers. There are numerous interventions available, many of which may have anecdotal evidence of efficacy but no scientific research establishing them as effective interventions. Many parents of infants and toddlers with autism are seeking highly intensive treatment programs such as Applied Behavioral Analysis (ABA). Research has shown that more-intense early intervention leads to significantly improved outcomes for children with autism spectrum disorders. These interventions, however, are not universally available and they are extremely expensive. Finally, there are not sufficient numbers of qualified providers statewide trained to work with infants and toddlers with autism spectrum disorders.
- 2. Service Variability among Localities:** This issue, addressed in the 2006 *Biennial Assessment* remains unresolved. Solutions Consulting Group in its 2007 *System of Payments Summary Report* cited a lack of consistency and uniformity in provision of services as among the challenges facing the Part C system. The consultants specifically note that a variety of contractual approaches within the localities do not support the requirement to ensure consistency and uniformity in compliance with Part C requirements. This finding on local variability in the availability and quality of Part C services echoes the conclusions of the 2004 Final Report of the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) Part C Infrastructure Task Force, which identified inconsistencies in the determination of Part C eligibility, evaluation of service needs, development and monitoring of required Individualized Family Service Plans, and delivery of services. These report findings, also supported by public comment in 2005 and 2007, indicate that training, skill levels, and caseloads continue to vary greatly across the state; and there is no consistent monitoring of Individual and Family Service Plan (IFSP)

implementation or effectiveness resulting in wide variability of service availability, intensity, and quality. In addition, families continue to report that they often do not receive the information or supports they need at the time that it is needed, resulting in a delay in gaining access to services that could benefit the infant or toddler. Obtaining Part C (or any) services needed by one's infant or toddler should not depend on the locality in which the parents live and work.

- 3. Service Payment and Rate:** In June 2007 the *System of Payments Summary Report*, prepared for the Part C program by Solutions Consulting Group, found that although more state general funds were infused into the Part C system, the program faces continued financial challenges, described earlier in the chapter. In addition to concerns that the number of children being served has not increased proportionately with the amount of funds infused in the system, additional issues include: (1) the lack of consistent, statewide data on the functioning of the Ability to Pay system and the overall cost of Part C services; (2) the wide variability of local contributions to the system, resulting in an uneven system of services depending on where the infant or toddler resides; and (3) provider reimbursement issues, including rates, processing delays, and variability of billing "units."

Specific provider rate issues affecting the Part C system are described by Solutions Consulting Group in the *System of Payments Summary Report* as follows, (excerpted): "Contractual arrangements between providers and local lead agencies are constructed locally. Rates for services are sometimes bundled and cover a whole month. Other times a unit rate reimbursement is used. Methodology for arriving at the rate varies considerably by locality resulting in reimbursement varying from \$50–\$150/visit without any criteria to warrant differences. The same holds true for reimbursement of evaluation/assessment services. Cumbersome third party billing procedures result in significant delays in reimbursement." The report also notes that few local lead agencies "reimburse for time spent in team meetings and consultations as are required by federal regulations."

- 4. Inadequate Use of EPSDT as Funding Source:** Directly related to the payment issues discussed above is the underuse of a primary payment mechanism. As noted in the chapter detail, there are numerous funding sources available for Early Intervention services. Early Periodic Screening Diagnosis and Treatment (EPSDT) through the state's Medicaid Program provides coverage for comprehensive medical and therapeutic intervention for children up to age 21 who are eligible for Medicaid. Many families do not explore the use of EPSDT because they are not aware of these benefits. Consistent reports from the Medicaid Waiver Technical Assistance Center show that many families are unaware that if their child receives services through Medicaid Waivers, they should have access to EPSDT because their child, once declared waiver-eligible, is also eligible for state plan Medicaid. Some children who are on a waiting list for the MR or DD Waivers may be eligible for the EDCD Waiver and if found eligible and funded would have access to EPSDT. Although the Department of Medical Assistance Services conducted an EPSDT outreach program, the program appears to remain underutilized and misunderstood.

5. **Lack of Qualified Providers:** Past funding limitations over the years have contributed to a dearth of qualified personnel, inadequate training, high turnover of Early Intervention providers, and competition for providers with local school divisions and other agencies that are able to pay more for services and staff. While funding for the system has increased significantly, capacity has not expanded to meet the need. Solutions Consulting Group in its 2007 *System of Payments Summary Report* noted a number of barriers to attracting and maintaining providers including, but not limited to, reimbursement issues, paperwork, and other requirements are seen as cumbersome by providers. Public comment received in the spring of 2007 indicated a limited choice of services and diminishing options, particularly in rural areas with limited resources. As noted above, the challenges of the increasing number of infants and toddlers diagnosed with autism spectrum disorders and requiring intensive levels of intervention have further strained the provider pool as have low provider rates.
6. **Organizational Conflict of Interest:** The Part C local lead agencies are responsible for ensuring that the local system of Early Intervention services is in place; and that the system meets all federal Part C regulations, state policies and procedures, and all fiscal and program assurances. In addition, the local lead agency, after receiving Part C funds from the state agencies, contracts or otherwise arranges with private entities for services, and can also be a provider in the local system. This results in an inherent conflict of interest, especially in those localities where the local lead agency is the **sole** provider of Early Intervention services.
7. **Gaps in Early Identification/Medical Practitioner Awareness:** Solutions Consulting Group in its 2007 *System of Payments Summary Report* noted the importance of early identification and Virginia's gaps in that area. An important aspect of early identification is continued physician awareness. Public comment continues to indicate that many pediatricians are reluctant to diagnose disability in young children, particularly for those who may be on the autism spectrum. Training and residency experience on disability identification in infancy and early childhood is a gap in most medical school curricula. Likewise, where probable disability is known, such as infants who are in the Neonatal Intensive Care Unit (NICU) unit for a significant time after birth, inadequate attention is given to addressing issues of potential long-term disability and to providing or arranging immediate Early Intervention services for babies exiting the hospital system.
8. **Challenges with Accountability and Correction of Noncompliance:** As reported in the chapter detail, Virginia's Part C system continues to have challenges with respect to compliance with federal requirements, and the Commonwealth is one of 17 states determined to be in the category of "needs assistance" in meeting the federal requirements of Part C. In reviewing areas of noncompliance and other challenges revealed by evaluators of the system, of most concern to the Virginia Board for People with Disabilities (VBPD) would be a need for improved accountability and oversight of local systems and accounting of the use of state general fund dollars.
9. **Inadequate Parent Education and Marketing of Part C:** As with other components of the disability service system, families cite inadequate access to information or a lack of

information as barriers within the Part C system. In the 1990s there was an extensive effort to market the Part C system to families and providers. The tagline “Babies Can’t Wait” became synonymous with the Early Intervention system. Posters, public service announcements, and literature were widely available. With the need to ensure that sufficient funding was available for direct service provision, marketing understandably became a lower priority. The lack of focus on providing adequate information on the Part C system, however, resulted in Child Find compliance issues (lower numbers of infants and toddlers served than appropriate or not served in a timely manner). In addition, the lack of a sustained public awareness effort has meant that that parents and professionals have less information available to them, and most seriously, infants and toddlers are referred to needed services at a later age than appropriate or not at all.

## H. Board Recommendations for Early Intervention Services

Part C Early Intervention services are an important component of the disability service system, addressing critical needs at the earliest age possible. The Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMSRAS) has engaged in a number of efforts designed to improve the Part C system, involving stakeholders at all levels. The Virginia Board for People with Disabilities (VBPD) Board supports these ongoing efforts. Many of the recommendations below represent areas that are already being reviewed by the Part C system. VBPD focuses below on those areas that it sees as most critical to improving the quality, quantity, and scope of services to infants and toddlers with disabilities.

### 1. Increase Accountability and Fiscal Oversight of the Part C Early Intervention

**Program:** As note in the chapter detail, the Commonwealth has infused significantly new funds into the system. This very positive step is commended. It is important, however, to determine why significantly more children are not being served despite increased funding. The Virginia Board for People with Disabilities (VBPD) recognizes that there may be a number of factors contributing to this including: (1) potentially increased costs of serving children in natural environments, including transportation costs; (2) potentially increased costs of serving children with more significant disabilities who may require intensive services, such as children with autism; and (3) possible reduced contributions from some localities as a result of increased state funding and the lack of any local funding requirement. These fiscal challenges need to be thoroughly examined and the use of Part C funds, federal, state, and where appropriate local, should be accounted for in a detailed, thorough, and transparent manner.

Rate issues are also a continuing challenge with respect to statewide service provision. VBPD recommends that provider rates be increased and that the rate structure fairly reimburse providers for their time. For example, transportation to and from the child’s residence should be reimbursable as an allowable expense so that a provider who spends an hour or more commuting is not penalized.

VBPD supports the comprehensive recommendations of Solutions Consulting Group with respect to family cost participation, funding allocations, and rate structures, and recognizes that these recommendations must be thoroughly reviewed and their impact on the system assessed prior to implementation. Their comprehensive report provides important guidelines for moving forward. VBPD particularly supports the recommendation that a Medicaid State Plan Amendment for Early Intervention Services through Home and Community Based Services under Early Periodic Screening Diagnosis and Treatment (EPSDT) be developed and that the expansion of financial eligibility for this home- and community-based service be increased to 300 percent of the federal poverty level. If implemented this would free up funds for services to infants and toddlers who are not Medicaid eligible.

**2. Enhance Quality Assurance Efforts to Improve Quality and Consistency of Services:**

The Virginia Board for People with Disabilities (VBPD) commends the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) for its work on a Quality Assurance System that began following the 2003 Infrastructure Task Force established by that agency. Much work remains to be accomplished, however. As noted in the *2006 Biennial Assessment*, a quality assurance system needs to address the training and caseload size of local service providers; identify where specific improvements are required in local planning, coordination, and service delivery by public and private providers; and promote existing best practices to eliminate service gaps and inconsistencies. All of these challenges remain at present. VBPD recommends that the following issues should specifically be addressed through quality assurance efforts: (1) Why are so many children being referred to the system who do not end up receiving Part C services? (2) Why are families refusing Part C services? (3) Are all children being accounted for via an accurate child count and if not, why not? (4) What specific services are children receiving and in what amount? (5) Is the new data system adequate for addressing these issues? (6) Is the state's monitoring and quality assurance system adequate to address the issues that have established Virginia as "needing assistance"?

**3. Eliminate Organizational Conflict of Interest:** VBPD recommends that the oversight and provider roles of the local lead agency be separated to eliminate conflict of interest.

Incentives should be expanded to encourage the expansion of the Part C provider pool, particularly in areas with limited resources to help ensure an adequate choice of providers. Within the current system, VBPD recommends that DMHMRSAS closely examine whether adequate "firewalls" have been established to maximize partnerships and mitigate conflict of interest issues that can negatively affect families.

**4. Improve Family Education Efforts:** VBPD recommends a significantly increased focus on outreach to families and on family education. This is needed to ensure parents are aware of the services available under Part C and of issues relating to the transition from Part C to school age (Part B) services. VBPD recommends development of a user-friendly *Guide to Part C Early Intervention Services*, similar in nature to the Guide developed by the Independence Center under a grant from VBPD on Medicaid Home and Community Based

Waivers. The Medicaid Waiver Guide is still being used by families and providers years after its first publication (having undergone necessary revisions) and is a consumer-friendly and accurate source of information in a changing environment.

- 5. Improve Medical Practitioner and Provider Education Efforts:** In addition to improving educational opportunities for families, significant effort should be devoted to educating providers. Families report that physicians, case managers, and social workers are often uninformed about the Early Intervention system and that referral to that system is delayed. VBPD recommends mandatory training of support coordinators and case managers so that they are able to give appropriate direction to families for needed services. Service providers should receive ongoing education that will enable them to implement best practices and become knowledgeable about disability-specific needs, such as working with infants and toddlers who have Autism.

Better education of medical practitioners, including physicians and nurses, who typically are the first individuals to interact with families needing services, supports, and referrals, is critical. The Part C system also needs to improve significantly the training and education of these practitioners regarding the services available through Part C and the importance of early identification. Physicians working with families whose children are in Neonatal Intensive Care Units (NICU) who are at risk of any developmental delay should be provided with information about early intervention. Although families may not “be ready” to receive this information and their child may ultimately not require services, the importance of early identification cannot be overstated. The Virginia Board for People with Disabilities (VBPD) recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) develops informational materials that are brief and concise in nature and that could be easily and inexpensively provided to all parents of infants who are in the NICU after birth. Finally, pediatricians and family practice physicians need additional education and training and readily available information regarding the Part C system. These practitioners are most likely to see infants and toddlers on a regular basis (both in private practice and public health clinics) and can be the key to identifying children in need of services at the earliest age possible.

- 6. Identify and Implement Best Practices in Autism:** VBPD recommends that as therapies and interventions are developed, the Commonwealth identify and support evidence-based practices, so that it can most prudently apply public dollars for interventions having the best outcomes and thereby save taxpayer money as well as provide the most meaningful support to families and children. VBPD supports the proposed study on Autism best practices currently pending in the 2008 General Assembly.
- 7. Implement Workforce Improvements:** VBPD recommends that a study of workforce needs in Early Intervention be conducted in light of provider shortages. Incentives should be developed to address the limited number of providers who are willing and able to provide services to infants and toddlers in their natural environment as required by federal law. The Governor’s Health Reform Task Force did an excellent job of identifying overall workforce

issues in the health arena; this type of study, albeit more limited, would be useful in ensuring access to quality Early Intervention services and transparency of such services. VBPD also recommends that data collected through the quality assurance system referenced above be used to determine situations in which workforce scarcity is caused by the inability of the local early intervention system to compete with the education system for qualified personnel and to recommend corrective actions and/or incentives for providers.

## Early Intervention Sources Referenced in This Chapter

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Louisiana State University: National Association of Special Education Accountability Monitoring: State Ranks—Part C:  
[http://www.monitoringcenter.lsuhs.edu/Stateranks\\_C.htm](http://www.monitoringcenter.lsuhs.edu/Stateranks_C.htm)

Virginia Department of Medical Assistance Services (DMAS): [www.dmas.virginia.gov](http://www.dmas.virginia.gov)

Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS): [www.dmhmrzas.virginia.gov](http://www.dmhmrzas.virginia.gov)

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